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## UTI pediátrica: o significado do cuidar na perspectiva da mãe

Pediatric ICU: the meaning of taking care in the mother's perspective

UCI pediátrica: el significado de cuidar en la perspectiva de la madre

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### ABSTRACT

**Objective:** To understand the significance of maternal involvement in the care of hospitalized children in the Pediatric Intensive Care Unit (PICU). **Method:** Descriptive study with a qualitative approach. Data were collected in October 2013, through semi-structured interviews with eight mothers. The reports were submitted to thematic content analysis. **Results:** Presented in four categories: "Recognition of maternal function"; "Care as a resource for coping"; "Learning to take care occurs observing and caring" and "Role of nursing staff". **Conclusion:** It is essential practitioners to be sensitive before the needs of mothers, resulting in hospitalization of children process, reinforce the positive aspects of their stay in healthcare settings, and at the same time, intervene on the negatives, thus providing a comprehensive, humane and qualified care to the binomial in the hospital environment.

**Descriptors:** Family Nursing, Intensive Care Units Pediatric, Mother-Child Relations.

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## RESUMO

**Objetivo:** Compreender o significado da participação materna no cuidado ao filho internado em Unidade de Terapia Intensiva Pediátrica (UTIP).

**Método:** Estudo descritivo, com abordagem qualitativa. Os dados foram coletados no mês de outubro de 2013, por meio de entrevista semi-estruturada, junto a oito mães. Os relatos foram submetidos à Análise de conteúdo modalidade temática. **Resultados:** Apresentados em quatro categorias: “Reconhecimento da função materna”; “Cuidado como recurso de enfrentamento”; “O aprender a cuidar se dá observando e cuidando” e “Papel da equipe de enfermagem”. **Conclusão:** Torna-se imprescindível que os profissionais se sensibilizem ante as necessidades das mães, decorrentes do processo de hospitalização dos filhos, reforcem os aspectos positivos de sua permanência no contexto assistencial, e ao mesmo tempo, intervenham nos aspectos negativos, proporcionando assim, um cuidado integral, humanizado e qualificado ao binômio no ambiente hospitalar.

**Descritores:** Enfermagem familiar, Unidade de Terapia Intensiva Pediátrica, Relação mãe-filho.

## RESUMEN

**Objetivo:** Comprender la importancia de la participación de la madre en el cuidado de los niños hospitalizados en la Unidad de Cuidados Intensivos Pediátricos (UCIP). **Método:** Estudio descriptivo, con abordaje cualitativo. Los datos recogidos en octubre de 2013, a través de entrevistas semi-estructuradas con ocho madres. Los informes fueron sometidos a análisis de contenido. **Resultados:** Presentado en cuatro categorías: “Reconocimiento de la función materna”; “El cuidado como un recurso para hacer frente”; “Aprender a cuidar se produce la observación y el cuidado” y “El papel del personal de enfermería.” **Conclusión:** Es esencial que los profesionales sean sensibles ante las necesidades de las madres, lo que resulta en el proceso de hospitalización, se refuerzan los aspectos positivos y los aspectos negativos intervienen, proporcionando una atención integral, humana y calificada para el binomio.

**Descriptores:** Enfermería Familiar, Unidad de Cuidados Intensivos Pediátricos, la relación entre padres e hijos.

## INTRODUCTION

The child, in the family's context is seen as the future and the achievement of dreams and father's expectations, transcending his own life. However, the advent of a serious child illness does break this routine, shaking meanings and perspectives, and triggering a series of contradictory feelings such as fear, anger and loss, which undermine the social, financial and emotional family's structures. The degree of dependence on care and support biopsychosocial can be as variable in front of the diagnosis, as many are the frames that are currently present in the context of health care.<sup>1-2</sup>

The child's hospitalization process in the Pediatric Intensive Care Unit (PICU) makes the family and, especially, the mother, who culturally assigns responsibility for the care of her child, go to develop internal resources to handle the process. Thus, promotes the coping with the disease and learning how to care, as well as the family adapt to the new status of the child.<sup>3</sup>

For the child, the mother's presence and care for it made in the context of PICU, promote a sense of security, since the hospitalization process often gives feelings of fear and anxiety, with a view to the realization of these units as local cold, strange and hostile.<sup>4</sup>

From the mother's point of view, taking care of the child is an activity capable of bringing encouragement before the illness and hospitalization scenario, minimizing feelings of guilt by illness, strengthening the bond/binomial relationship, coupled with the benefit of care learning to be performed to the child. This in turn promotes greater safety for the child, so that it has greater acceptance and adherence to treatment, contributing significantly to reducing the length of hospital stay.<sup>5</sup>

Considering, therefore, the numerous benefits of maternal care in this environment, it is necessary a more effective professional contribution. It is essential that the mother is stimulated and placed in care by the hospitalized child as early as possible, always taking into consideration the fear, anxiety and maternal inexperience that emerge from the process of performing simple and complex care in the context of PICU.<sup>2</sup>

Thus, in order to release a care focused on the interaction between mother, child and health care professionals, it is necessary to establish a relationship of empathy, and professionals working in the intensive care units need to consider several factors.<sup>6</sup>

Given the above, and considering the specifics of nursing care in pediatric intensive care setting, and the observation of the mother's aid involvement in the general care of the hospitalized child, it was proposed to develop this study because the mother perceives that the shared care of the hospitalized child in the PICU may contribute to the planning of nursing care humanized and integral to the binomial.

So, the objective of the study is to understand what it means for the mother to participate in child care hospitalized in PICU.

## METHOD

Descriptive and exploratory study, with a qualitative approach. Qualitative research begins with broad exploratory goals that provide a focus for the study without emptying aspects of experience that might be deemed important. It is an inductive and not deductive research, and participants are selected for their experience regarding the phenomenon of interest to be studied.<sup>7</sup>

The study was conducted in a teaching hospital located in Northwest Paraná. The institution is classified as medium-sized hospital and tertiary care, being accredited to offer medium complexity service to cities from the 15th Regional Health and other regional state. Therefore, currently it has 123 registered beds, of which 27 pediatric patients.

The PICU there since January 2004, and has six beds for the care of children aged 29 days to 14 years incomplete,

possibly absorbing part of the demand of neonatology. The health team active in the unit consists of 11 nurses, ten nursing technicians, nine pediatricians, three physical therapists, two social workers, a psychologist and a nutritionist.

The study participants were eight mothers who had their children admitted to the PICU during the data collection, and who met the inclusion criteria: age less than 18 years and son of the hospital stay more than 15 days. The minimum hospitalization time was fixed to ensure a minimum experience in the context investigated, to allow the participants discuss the central theme of the study.

Data were collected in October 2013, in reserved place – a room attached to the unit, through semi-structured interviews, which were recorded with the consent of the mothers, with an average duration of 20 minutes. During the interviews we used a script with questions that addressed socio-demographic characteristics, and a guiding question: “What does it mean for you to participate in the care of your child in the PICU?”. For the processing of data, interviews were transcribed and subjected to content analysis, thematic modality, following the phases of pre-analysis, material exploration, analysis and interpretation framework.<sup>8</sup>

All recommendations of Resolution 466/2012 of the National Health Council were followed and data collection started after approval of the project by the Standing Committee on Ethics in Research Involving Human Beings of the State University of Maringá, an opinion on 410846/2013. In order to preserve the identity of the participants, mothers were identified with fictitious names, assigned according to the sequence of interviews and letters of the alphabet (Amalia 1; Bianca 2, Catherine 3; Daiana 4; Eliza 5; Flavia 6; Gisele 7; 8 Helena). All participants signed a free and explained consent form in two ways.

## Results and Discussions

The eight mothers in the study were relatively young (aged 17 to 39 years and average 29 years), six had traditional family the nuclear type, five married, two were single and one in contact with the child's father; five of them had two children, two had a son and the other had five children. Four mothers had at most completed elementary school and the other four complete high school. Regarding the occupation, three participants were housewives, two seamstresses, one diarist, a saleswoman and a community health agent. Family income varied from one to six minimum wages and seven lived outside the city of Maringá.

In relation to hospitalized children, five were male, aged between six months and six years. Seven of them had a history of chronic disease and had been the victim of domestic accident, requiring provisionally complex care. The staying varied between 30 and 365 days.

From the process of analyzing the reports, which were about the main theme of the study, emerged the following thematic categories: “Recognition of the maternal role”;

“Watch as a coping resource”; “Learning how to take care takes watching and caring” and “Role of nursing staff.” The categories make up so the corpus of the analytical process and will be detailed below.

### Category – Recognition of maternal function

In the mothers' accounts it was evident the importance attributed to her presence with the child in this singular moment, because it is considered source of support, comfort and safety for the child. Furthermore, they consider that being present, monitoring the child's treatment and providing care enabled them to personal growth, and give them courage to face the difficulties imposed by the disease and the long length of stay:

*“I am prepared to look after, I'm the mother”, Catherine;*

*“She is attached to me, I'm the mother... so I think she feels safer with the mother having contact with her than with the nurses”, Flávia;*

*“The mother's participation is to be together, I believe it helps and I also grow a lot... I'm here with her, it is important then”, Gisele.*

Currently, follow the restoration of a hospitalized child in a PICU is a common practice in the hospitals. However, mothers tend to feel more secure in this unfamiliar environment, and sometimes hostile, as it allows and encourages it to engage, indeed, the role of mother. This condition manifests when you give autonomy to carry out the care of the hospitalized child. Thus, autonomy means, to the mother, that the child belongs to her, since she is able to act directly as a fundamental caretaker of the sick child.<sup>9</sup>

Being present and monitoring the treatment of the child provides security to the mother and family. Furthermore, the presence and family more active role enables its members, realize that all that is possible for the child is being done, which helps even in minimizing the possible guilt of their illness and promoting wellness of child.<sup>3-4</sup>

When the mother is poorly placed in care of the child hospitalized in PICU, there is a problem arising from the weakening in the bond already established with the child or in the case of newborns, incorporation of the maternal role, as the consolidation of affective ties between mother and baby is little stimulated:

*“At first I felt kind unable to care for her, because it was more the team that took care of her, bathed, took care of the navel, cleaned gastrostomy. I took medicine, milk, changed things into simple. I do not entirely her mother felt there, I even helped but it was not her mother... I did not go to her mother in the first months of life”, Daiana.*

Daiana's report allows realizing how important it is for mothers to perform care for their children during hospitalization. It also shows that the role of mother and its unique meaning encourage her to care for the child, and this paper, the major motivating factor to withstand adversity, tensions and complexities present in intensive care units.

In another study, conducted at the same institution, the bond formation between mother and child was more intensely strengthened as increased the type and duration of care provided by the mother. Thus, the frequent realization of care by the mother, unleashed the most intimate contact with the child, encouraging the creation and strengthening of emotional bonds between them.<sup>10</sup>

This predictive was also found in a study conducted in Colombia, where mothers, when realizing prevented from playing basic maternal care, reported feelings of uselessness, while expressing the feeling that their children no longer belonged to them.<sup>11</sup>

Thus, it is necessary to include more and more mothers in this care context, giving them the opportunity to exercise activities that strengthen them as main caretakers of children, strengthening their autonomy.

### Category – caring as a facing resource

The speeches show the presence of negative feelings such as sadness, mental suffering and anguish that accompany the hospitalization process of a child in the PICU. The experience of staying in an unfamiliar environment, coupled with the imminent risk of losing her child, makes the mother mobilizes internal resources to face the situation. In this context, the possibility of some care by the child emerges as an important coping resource:

*"I take good care of it ... it was very hard for me, the way he came. Take care of it helps a lot, all the problems I had, of fear, so... I feel good", Catherine;*

*"Help me (can be careful), it gives me more strength to live life", Eliza;*

*"I have to go learning... I started getting longer, more and more, until the time I spent getting all the time with her, because I feel like she needs me and I need that", Helena.*

In a study with mothers of hospitalized children, it was found that staying with the child throughout the hospital made mothers feel co-responsible for his/her recovery, and this fact was identified as important in mobilizing domestic and personal resources to face this process.<sup>12</sup>

The reports of mothers also showed that participation in the child care made rise the has feelings of self-worth by providing them the recognition of their skills and increase self-esteem, as shown in the following reports:

*"I'm finding myself important because I take care of my son, and they are teaching me. I'm not so alone in a corner, they are with me, teaching me. I quite like", Amalia;*

*"I feel useful because, well, at first, I just stared, then not, then I started practicing... I feel accomplished because I take care of take care of it., Helena;*

*"I help, I think I'll handle it well, help me also to take care of it, so that today he's fine", Catherine.*

In an intervention study that aimed at inserting and keeping the mothers in care of their children admitted to the PICU, they assimilated the proper way to care and with time performed in a safe and responsible manner.<sup>10</sup>

It should be noted that, by including the mother in the execution of basic care to the child, she feels active, responsible and useful, perceiving herself as a fundamental caregiving.<sup>9</sup> This points to the need for greater encouragement of this practice by the nursing professionals, since these stimuli intensify the links between binomial and nursing staff, and enable the promotion of care with better quality.

### Category – Learning how to take care takes watching and caring

The mother staying with the child in the PICU contributes to the learning of simple and complex care that needs to be provided to the child. Commonly, the learning process takes place during hospitalization, and sometimes after discharge, at home, in front of maternal observation during the execution of care provided by the health team.

*"Each time I get a little knowledge, you look, watch, if you have any questions question... there will already picking up ... and I was wondering how it is, how it is, so I've been taking the base.", Flavia;*

*I'm looking for learning... At home it going to need me, then I see nurses as my mirror. In the beginning, when the physiotherapist would suck, I was looking for when it was my time I will not be so afraid", Gisele;*

*"I want to learn, so I stand there watching and learning more, so I can take care of it better", Helena.*

One study also conducted with mothers during hospitalization of their child in the ICU pointed out that they were seeking to learn how to care for the child during the time that it remained in the institution. Therefore, accompanying the care given to the child by different health professionals and, from observation, built new bases for their own knowledge.<sup>13</sup>

The reports show the concern that exists in relation to care, especially as the possibility of discharge is coming

next. In fact, the hospital discharge is a highly anticipated event, since it is the recovery of the child, but also means the need for the family, especially the mother, to take simple and complex care in the home environment. Being the mother culturally recognized as the primary caregiver of the family members, the high prospect was a great motivator for care learning:

*"They make the dressing. I see them doing, I'm learning to be able to do at home. They taught me to suck him, then I learned, I now know how to do at home, I'll suck it at home", Amalia;*

*"Before, when he was sedated were only them; now, I have to learn, because I have to do at home", Bianca;*

*"At first happens an insecurity... but then, I have been losing fear because I had to do it for him, care was passed to me and my husband. They explain that we have to learn to look after him at home", Gisele.*

This fact agrees with those found in the literature, in which the interest in learning to perform the necessary care to the child quickly, was related to the need for running them at home.<sup>10</sup>

Tangentially to the discussion, the literature indicates that mothers show is strengthened and trained in relation to the care that will be held for them at home, as their active participation in hospital care. It is, therefore, an effective way to encourage self-reliance in developing the care of children at home, after alta.<sup>14</sup>

These findings point to the importance of the nursing staff to worry about exploiting families, and especially mothers, about the care through a comprehensive and motivating stance, aiming to promote the empowerment and maternal autonomy for care.

### Category – Role of Nursing Team

The analysis of the reports of the participating mothers identified the important role of nursing staff as supportive of maternal insertion in the care process.

This is because the testimonials confirm the recognition of the work of these professionals in the support and realization of a qualified care and especially the approach they do, which is marked by the stimulation and education of caregivers mothers:

*"The whole team helps me ... so the more they encourage me, more will I have to learn to take care of it.", Helena;*

*"At first the nurses helped me a lot, I was afraid ... But after we talked a lot and helped me cope.", Gisele;*

*"I do everything: bathe, change everything. The first time I felt a little scared, but it was going... It was beautiful! I*

*help a lot to cope with it all, because it's hard... They talk, do this, do that, and I think I do all right", Catherine.*

These findings corroborate the results of another study, which shows that the nursing staff cooperates with mothers, gradually encouraging physical contact with the hospitalized children and enabling them to gain confidence to be able to run from simple care to the most complex, with monitoring and supervision of staff.<sup>11</sup>

A study conducted in Rio Grande do Sul highlighted and stressed that this confidence the family has in the nursing team provides security and peace of mind to parents. It also noted the impact of qualified and humanized care of the ICU nursing staff Neonatal face the child's hospitalization process, to encourage the search for internal resources.<sup>15</sup>

It is noteworthy that, attention is perceived differently by mothers who, on one hand consider the care provided by excellent nursing staff, by providing security information, knowledge and tranquility to watch the child:

*"During the day I take care of him and at night I will sleep soundly though, because I knew that everyone was there watching him", Eliza.*

*(Hospital) Began to be like my house, I got to know everyone in one way or another all help me, they understand when I'm sad, silent, or happy", Gisele.*

On the other, they come up against the fact that this type of approach and not be adopted by all team members:

*"I did not feel afraid, but I saw some people treat children as an obligation to make and that's it, I saw some people doing it and others treat my girl with love, I did not feel comfortable seeing she not moving", Daiana.*

This ratifies the findings of another study that concluded that the interaction with the nursing staff is perceived differently by different subjects. On one side, are perceived support, attention, peace and security on the team and, on the other, not cozy relationship that generates discomfort and insecurity.<sup>15</sup>

The diversity in the way of perceiving the performance of the team in the assistance provided in PICU beyond the possibility of actually having professionals who for one reason or another may have inappropriate attitudes, must not only be accepted but understood. This fact leads, by example, the importance of considering the uniqueness of the experience of each family in coping with the disease. Therefore, it is essential to understand the family dynamics, their behavior, their feelings, their weaknesses and the meanings that

this experience has for her. From there, plan a tour that encompasses the individual needs of each family.<sup>13, 16</sup>

Taking into account these aspects, we should note the key role of nursing as a facilitator of early contact between mother and child hospital, aimed at strengthening the bond and attachment. In addition, a welcoming environment, that favors building a relationship of trust and commitment to family, highlighting its special features, as human beings vulnerable to the disease and hospitalization, is crucial to ensure a holistic look and full on this reality, with a view to the qualification of care.

## CONCLUSIONS

The care shared in the intensive care unit environment provides mothers recognition of their maternal role, which is lost due to the hospitalization. Negative feelings are overcome as the mother is included in the simple care and, gradually, in complex with their children because they feel useful and valued, and this perception is an important coping strategy.

With regard to the learning process, it is emphasized that the stay of mothers in PICU favors the observation of care provided by the health team, which are gradually assimilated, seized, and later played for them. It is noteworthy that the concern of mothers focuses on learning to properly carry out the care they need give the child after hospital discharge, at home and without the support of a specialized health care team. This perception makes this the main motivating event for the care learning.

In this sense, the role of nursing staff as supportive to the maternal involvement in care during hospitalization is recognized by mothers, who expressed feelings of gratitude, which reveal the need for the accompanist of the children admitted to the PICU to be considered and assisted throughout the hospital stay.

It is essential that nursing professionals aware up and raise awareness that the family should be incorporated into the care provided by the nursing staff, considering its uniqueness and dynamics. In this sense, when it is suggested to consider the mothers' expectations and concerns on the learning process, so that professionals provide a comprehensive care targeted and qualified, which values the real needs of the child and his/her family.

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